

Alzheimer's Disease: Native Americans

Crow Eldercare
Serving Native Americans
on the Reservations



Developed by the
Crow Nation, the Montana
Department of Public Health and
Human Services, the Montana
Division of Senior and Long
Term Care Services

Alzheimer's Disease Demonstration Grants to State Program

A Program of the U.S. Administration on Aging

The Crow Eldercare Project is located within the Tribal Health Department on the Crow Reservation. Using a case management model of service provision, Crow Eldercare has a registered nurse and social worker team to provide initial assessments, care plans and ongoing support to families with dementia care needs. The team is supervised by the Tribal Health Director.

The team coordinates in-home respite services and a monthly group adult day program for Native American elders and their families. Using a case management program developed in Idaho, the Montana Alzheimer's Demonstration project and the Crow Tribe collaborate to provide services to persons with dementia. Services are delivered on the Crow Reservation by Crow staff. In addition to providing outreach and education about dementia issues and needs, the team members provide assessments, link families to services, offer in-home respite and group day respite and serve as resource specialists on the Crow Reservation.

Building Trust within a Bicultural Environment

Building trust among partners is a significant aspect of the project. The lead agency, the Division of Senior and Long Term Care Services, structured the project ownership and funding mechanisms to operate through the Crow Tribal leadership. The Area VII Agency on Aging is the liaison between the State agency and the Crow Tribe. The bicultural AAA staff helps negotiate differences in understandings and expectations between the different cultures. Having a bicultural liaison is invaluable to the success of the project.

Serving Crow Elders

The case management model of professional assessment, supported by in-home respite care, eliminates many barriers that rural and culturally diverse persons face. These barriers are overcome by insuring prompt access to knowledgeable professionals, by setting convenient times and places for service delivery, by insuring privacy in requests for help and plans for care, and by creating culturally friendly support strategies.

To develop the Alzheimer's Demonstration project, a task force (Dementia 2000) was formed to identify the needs of rural caregivers. The task force recommendations were instrumental in designing a project to provide access to professional assessments, to provide support and education to family caregivers and to present service in a way that is acceptable to the elders receiving the services. Barriers to accomplishing these things included long travel distances, scarcity of telephones and the cultural expectations of caregivers and elders.

The Crow Tribe was a willing partner in this project. Initial information was limited about the extent of need for services on the Crow Reservation. The Alzheimer's Demonstration project staff began by acknowledging that it was important for needs to be defined by the Crow Tribe and for services to be integrated into the Crow Reservation structure and delivered by tribal members.

Despite the fact that Montana has a large Native American population, there were no specific services targeted to dementia

needs. The model used in Montana maximized the independence of the elders with dementia while providing respite time for their caregivers. There were no restrictions concerning age or living situation (with family or alone) but a diagnosis of dementia was required within 90 days of service initiation.

How the Program Was Established

Service staff were hired by the Crow Tribe and trained on dementia issues using project funds. Staff attended national meetings that acquainted them with other providers and dementia networks. Additionally, project staff worked within the existing service infrastructure on the Crow Reservation (Indian Health Services, Tribal Health, Senior Center, Bureau of Indian Affairs, the Community Health Representative). This link provided information to clients and referrals to the new project.

At the state level, the Division of Long Term Care Services links the Native American infrastructure with the Alzheimer's disease and aging infrastructures through collaborative funding opportunities. The Division of Senior and Long Term Care Services works with many organizations to advance awareness of the needs of Native American elders. The office seeks to maintain high visibility for Native American needs in regional, state and federal meetings. When Native American issues are not formally included in the meetings, arrangements are made to have Native American music or dancers at the meeting.

Barriers and Obstacles

The project at first struggled for recognition, but an early site visit by the federal Alzheimer's Demonstration Project Officer impressed the Crow Tribe with the importance of the project and the Crow Tribe gave support to the undertaking. The project was not always a simple thing to do because what works well in other Crow Tribal matters did not generalize to the new project. For example, the Crow Tribal government holds elections every two years and an election can result in a complete change of personnel. These staff changes may influence negotiations and working relationships among partners who may have to begin anew. Frequent changes would also present major training and education problems for a new project. Because of the potential for staff changes with new governments, the initial contract insured that the case management team and respite workers were nonpolitical positions and thus not open to reappointment under changing political administrations.

Some Crow tribal members saw the new project as an employment opportunity. Others saw it as money that would be here today and gone tomorrow. These perceptions led to various interpretations of service delivery. The State took a flexible approach to these problems and accepted the idea that tribal interpretations that are appropriate within the Crow culture could be functional in implementing new projects. Thus, both the State and the Crow Tribe reinforced the need for flexibility and openness to different approaches to meeting project goals.

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Specific programs were sometimes influenced by cultural norms and implemented in unusual ways. For instance, adult day care became family Bingo. Respite care became help with a variety of tasks (housekeeping, laundry, errands) because families do not want to be relieved of hands-on-care.

Additionally, Native American culture is family oriented and not age segregated. Service activities must be open to intergenerational involvement.

Community awareness of the needs of persons with dementia and services available through the Crow Eldercare program was low in the beginning. Project staff initially used a general needs of seniors survey to contact as many elderly individuals in the Crow Tribe as possible. This allowed project staff to assess the needs of the Crow elders in a non-threatening manner. It also allowed team members to refer appropriate individuals to the Crow Eldercare program and provide dementia education to families.

Project staff also made personal visits to service agencies and key service providers on the Crow Reservation to introduce the project. The staff involved nontraditional service providers in these visits, including law enforcement representatives and specialists in children's programs. The visits were often with employers of the family caregiver. All referrals were followed up with home visits.

There is a lack of knowledge about dementia among Native American providers and families. In general, Native American culture accepts a variety of elderly behavior as appropriate. Early dementia symptoms are sometimes explained away as an elder becoming

childlike in preparation for death. In the recent past, few Native Americans lived to be elderly. Consequently, many Native Americans have little experience with an elder in the family. Not understanding dementia as a disease makes it difficult for families to ask for help.

Cultural protocols for gender behavior sometimes create barriers to service. Some Native American cultures have gender codes about who may speak to whom. Among the Crow, clan membership dictates interpersonal relationships. Communication with in-laws provides an additional dynamic. Often, when the team meets with a family when doing assessments of male elders, information must flow through appropriate relatives.

Tribal government practices obviously differ from state government. Each entity has to be open to negotiating between and among the different structures (financial, bureaucratic, etc.) while dealing with a third party-the federal government. Flexibility is the key to maintaining a successful working relationship. Creating clear goals and mutually developed objectives helps maintain the focus. Additionally, because both the tribal government and the Division of Senior and Long Term Care Services contribute financially to the project, everyone involved has an interest in seeing the project succeed.

Who Benefits from the Crow Project?

Project benefits are apparent at multiple levels. Clients receive dementia specific respite care and adult day care services. Families receive education and support.

Thus, the project increases awareness among tribal members. Dementia resources now exist where they did not exist before the Alzheimer's Demonstration project.

Benefits to the Crow Tribe include resources for linking Crow Eldercare services, employment for seven tribal members, education regarding dementia and related disorders, and training for direct care staff on dementia care, elder abuse, nutrition, and personal care. The Crow Tribe also receives state and national recognition for innovative service provision. Crow Tribal staff is integrated into state aging network activities and professional conferences.

State level benefits include increased awareness of dementia and a stronger presence of Native Americans at aging network events and cultural diversity workshops for providers. Working relationships have been strengthened among the members of the aging network and the Crow Tribal government. The project also promotes interaction among the seven reservations in Montana. Additionally, the Alzheimer's Association is linked to the Crow Tribe as a further resource.

Perhaps the strongest impact of the project is the integration of aging and dementia needs into the Crow Tribe's service agenda. The Crow Tribe recently received a settlement from a lawsuit which enabled the Crow Tribe to implement its own elder programs. Building on the awareness and expertise developed through the Crow Eldercare program, the Crow Tribe is using some funds from the lawsuit settlement for aging and dementia needs. The Crow Tribe is now funding the Crow Eldercare Program and is further developing its

capacity. Previous clients are continuing to receive care through the new project. The Crow Tribe has hired the respite aides trained under the Alzheimer's Demonstration project to provide for the needs of anyone who requests help. Freed from traditional service delivery funding constraints, there are no eligibility criteria for the new respite service. If tribal members request service, they are served. Additionally, the Crow Tribe has built a nursing home and is developing it as another service resource within the community.

Costs and Support for Crow Eldercare

Three costs determine the quality of the project: staff, training and travel. Respite staff costs are determined by the client case load. Some staff costs can be handled by contracts. Training money is critical in facilitating staff education. Travel money is needed to provide in-home respite for clients in rural, isolated areas. Some costs such as clerical support, office space, phones and equipment can be handled by in-kind services. The most critical resource for success is the leadership within the Crow Tribe. To be successful, the leadership must provide political as well as economic support for outreach and referrals to the project.

Keys to Success

1. The project is intergenerational in keeping with Native American culture. For example, grandmothers are often in their thirties and age distinctions are not as obvious as in some other cultures.
2. Services must respect personal and cultural traditions. For example,

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food at meetings is important (in keeping with Native American culture, food represents a form of hospitality and respect).

3. Time is viewed with more flexibility in the Native American culture. Visiting can be as important as conducting business. The cultural importance of storytelling is respected.
4. Decisions are best made in an open exchange.
5. All aspects of a problem must be talked through. Shortcuts are not functional in making decisions.
6. The Crow Reservation has an informal communication system like many small communities. The Crow Tribal culture is clan-based and everyone knows everyone else or is related in some way.
7. The project is flexible enough to help with other concerns as well as dementia issues. Dementia needs may have a low priority for Native Americans who are facing problems with diabetes, child health and alcoholism.
8. The project recognizes that many family members experience multiple stresses associated with unemployment and poverty.

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The Administration on Aging is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers through the national aging network of state and local agencies on aging, tribal organizations, service providers and volunteers.